

The Children's Hospice & Palliative Care Coalition

Findings and Recommendations

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DRAFT

Children's Hospice & Palliative Care Coalition (CHPCC) has successfully engaged a variety of stakeholders, along with the California Department of Health Services (DHS), in documenting the problems and analyzing the options for improving access to palliative care services for critically ill children. In order to accomplish this, CHPCC developed and utilized information from families, providers and payers that documented the problems with the current system. It also developed options for change, communicating with Centers for Medicare and Medicaid Services and researching the established and developing programs of other states. Together, with leaders from the children's health provider community, CHPCC analyzed the policy options available to DHS to address the needs of children and families.

A. Findings of Fact:

As a result of gathering information and analyzing options, CHPCC is able to make the following finding of fact regarding hospice and palliative care services for children in California:

1. Current federal hospice eligibility requirements prohibit coverage and reimbursement of home hospice and palliative care for a child unless the following occur: a physician and the child's parent(s) or legal guardian 1) declare in writing that the child has less than six months to live and 2) agree to forgo treatment intended to cure the disease or prolong the life of the child.
2. According to the Institute of Medicine and the American Academy of Pediatrics, the application of adult federal hospice eligibility requirements to children results in:
 - a. Families left with the cruel and inhumane choice between "trying to cure the child's disease" or "managing pain and focusing on quality of life."
 - b. An unnecessary division between curative treatment and home hospice and palliative care which causes confusion, anxiety and stress among medical professionals, caregivers and families.
 - c. Children undergoing painful procedures and suffering from the symptoms of advancing disease without adequate relief, despite the fact that modern medicine has the means to relieve their pain and improve most symptoms.
 - d. Denial of the necessary services critical to children and their families including 24-hour on call nursing, respite care, pain management, expressive therapies, ongoing psychosocial support, and bereavement services.
 - e. Families caring for children with life-threatening conditions at home having to administer medications and deal with emergency situations without adequate support, resulting in an excessive number of preventable emergency room admissions, undue stress and hardships for the families and, most importantly, compromising the health and lives of children.
 - f. Families receiving sporadic and, at best, minimal access to psychosocial services.

3. A pediatric palliative care knowledge base exists and is growing among California's children's hospitals, home health agencies and hospice providers, thanks in part to the efforts of CHPCC. However, because there is no effective system of reimbursement for this care, pediatric home hospice and palliative care is not yet widely available and utilized.
4. Pediatric home hospice and palliative care could be provided by a qualified agency and reimbursed by Medi-Cal, concurrently with CCS reimbursed home health services and transitional care provided outside the hospital.
5. Concurrent reimbursement for curative treatment and home hospice and palliative care is fiscally responsible. New costs will be offset by the reduction of preventable emergency room and hospital admissions, reduced duplication of services and resources, better coordination and continuity of medical treatment, and a system that offers families and physicians the opportunity to choose the most appropriate setting for care such as home, hospital, clinic, or licensed nursing facilities including skilled nursing facility, nursing facility and congregate living health facility.
6. Improving care for children with life-threatening conditions and their families should help improve care for all children and families.
7. Better care for medically fragile children is possible now, but we also need better data and scientific knowledge to guide efforts to deliver more effective care, educate professionals to provide such care, and design supportive public policies.
8. Should the demonstration meet the goals described in the waiver as approved by CMS, DHS should consider making this benefit available to all children statewide.

B. Recommendations

CHPCC recommends that the California Department of Health Services provide a Children's Hospice and Palliative Care Benefit to children enrolled in public insurance programs primarily Medi-Cal and Healthy Families who meet certain specified criteria. Specific recommendations regarding the structure and financing of this new benefit are as follows:

1. Eligible Children:

As a condition of receiving the new Children's Hospice and Palliative Care Benefit, children should not be required to forego curative treatment, nor should they be required to have a specific number of months or years remaining in their life expectancy. Children should be eligible to receive curative and palliative care simultaneously and should begin receiving palliative care and hospice services at a time in their treatment when they and their family can benefit from them, not exclusively when they are near death.

The population served under this new benefit will be the medically fragile child who meets the following criteria:

- a. Under the age of 21 at the time of admission;
- b. Has been determined eligible for California Children's Services or Genetically Handicapped Persons Program benefit and qualifies for Title XIX or Title XXI (or successor programs) based on family income and resources;
- c. Has been determined by a physician familiar with the child's condition and care to have a life-threatening or potentially life-limiting medical condition so serious it is unlikely that the child will live to adulthood.
- d. The child's family and/or legal guardian(s) is willing to receive services from a qualified agency available under the benefit created by this Act.
- e. Has at least one family member/guardian caregiver who is trained (or willing to be trained) and available to provide care at home.
- f. Has a home available that is safe and can accommodate the necessary medical equipment and personnel needed to provide care in the home.

2. Services and Benefits:

In addition to the full array of Medi-Cal/CCS benefits currently available to the child, the Benefit will also provide the following services administered by a qualified agency's (see C, 4 below) interdisciplinary team:

- a. Care Coordination (between healthcare providers including hospitals and community hospices/home health/community support agencies)
- b. Pain and symptom control management
- c. On-call, in-home skilled nursing support services available 24/7
- d. In-home personal care by a home health aide
- e. Child life specialist
- f. Individual counseling
- g. Respite Care
- h. Family/caregiver consultation
- i. Family/caregiver counseling
- j. Spiritual Care
- k. Bereavement Services
- l. Volunteer Services

3. Financing and Administering the Benefit:

- a. DHS should work to secure Federal Financial Participation from CMS, through the 1915 Waiver process.
- b. To the extent necessary it should submit amendments to the Medi-Cal State Plan including, but not limited to, proposals to modify the coverage and reimbursement for pediatric hospice and palliative care services.

DHS should be able to pay for the State share of the new benefit costs using its existing budget for medical assistance. This should be possible due to the savings anticipated from improving coordination of services and the reduction CHPCC

- c. of expensive or unnecessary and/or duplicative services that are now being provided to these children.
- d. DHS should work closely with potential service providers and other stakeholders to establish the Waiver terms and conditions. Widespread participation in Waiver design will help to assure that the new benefit will be implemented robustly once it has been approved by CMS. Having a sufficient number of enrolled providers and children, will help to change the medical care delivery paradigm for critically ill children, will permit a definitive evaluation of the demonstration project and will meet the needs of children and families.

C. Definition of Terms:

In order to educate the policy makers and improve our ability to dialogue about this issue, the CHPCC developed the following definitions of relevant terms:

1. Palliative Care - “Palliative” refers to medical treatment, interdisciplinary care, or consultation provided to the patient or family members, or both, that has as its primary purpose preventing or relieving suffering and enhancing the quality of life, as described in subdivision (b) of Section 1339.31, of a patient who has an end-stage medical condition.
2. Eligible Child - an individual under age 21 with a life threatening condition who is entitled to benefits under California Children’s Services or the Genetically Handicapped Persons Program and qualifies for Title XIX or Title XXI (or successor programs) health care benefits
3. Physician - a person licensed as a physician and surgeon by the California Medical Board or by the California Board of Osteopathic Examiners
4. Qualified Agency- an agency licensed by the State of California to provide hospice or home health services and certified to provide hospice through the Centers for Medicare and Medicaid Services.
5. Child Life Specialist – certified professional who is specially trained to help children and their families understand and manage challenging life events and stressful healthcare experiences through developmental, educational, and therapeutic interventions.
6. Interdisciplinary Care - care provided by an interdisciplinary team designed to address the physical, social, emotional and spiritual needs of a patient.
7. Interdisciplinary Team - the hospice care team that includes, but is not limited to, the patient and patient’s family, a physician and surgeon, a registered nurse, a social worker, a child life specialist, a volunteer and a spiritual caregiver. The team shall be coordinated by a registered nurse and shall be under medical direction. The team shall meet regularly to develop and maintain an appropriate plan of care.
8. Care Coordination Services - services that provide for the coordination of, and assistance with, referral for medical and other services, including multidisciplinary care conferences, coordination with other providers involved in care of the eligible child, patient and family caregiver education and counseling, and such other services as determined to be appropriate in order to facilitate the coordination and continuity of care furnished to an individual.

9. Skilled Nursing Services - nursing services provided by or under the supervision of a registered nurse under a plan of care developed by the interdisciplinary team and the patient's physician and surgeon to a patient and his/her family that pertain to the palliative, supportive services required by patients with a terminal illness. Skilled nursing services include, but are not limited to, patient assessment, evaluation and case management of the medical nursing needs of the patient, the performance of prescribed medical treatment for pain and symptom control, the provision of emotional support to both the patient and his or her family, and the instruction of caregivers in providing personal care to the patient. Skilled nursing services shall provide for the continuity of services for the patient and his or her family. Skilled nursing services shall be available on a 24-hour on-call basis.
10. Home Health Aide Services - those services described in subdivision (d) of Section 1727 that provide for the personal care of the terminally ill patient and the performance of related tasks in the patient's home in accordance with the plan of care in order to increase the level of comfort and to maintain personal hygiene and a safe, healthy environment for the patient.
11. Respite Care - relieving the primary caregiver by providing an alternative caregiver for a short time when necessary on an occasional basis consistent with the plan of care. Respite care could be home or facility based in a DHS licensed facility as described in Section 2, N.
12. Bereavement Services –services available to the surviving family members for a period of at least one year after the death of the patient, including an assessment of the needs of the bereaved family and the development of a care plan that meets these needs, both prior to and following the death of the patient.
13. Volunteer Services – services provided by trained hospice volunteers who have agreed to provide services under the direction of a hospice staff member who has been designated by the hospice to provide direction to hospice volunteers. Hospice volunteers may be used to provide support and companionship to the patient and his or her family during the remaining days of the patient's life and to the surviving family following the patient's death.
14. Transitional care – skilled nursing care provided in a DHS licensed nursing facility including skilled nursing facility, nursing facility or congregate health living facility enabling families to transition smoothly from hospital to home.